REVIEW OF THE MEDICAID 1915(c) HOME AND COMMUNITY BASED SERVICES WAIVER PROGRAM LITERATURE AND PROGRAM DATA

Final Report

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REVIEW OF THE MEDICAID 1915(c) HOME AND COMMUNITY BASED SERVICES WAIVER PROGRAM LITERATURE AND PROGRAM DATA

This report reviews literature and provides a brief summary of current program statistics for the Medicaid 1915(c) Home and Community-Based Services (HCBS) Waiver program. First authorized in 1981 to allow states flexibility to offer different types of services to individuals with chronic disabilities, the HCBS Waiver program has become the primary mechanism for states to provide Medicaid-funded community-based, long-term care services to targeted populations.

This review is intended to provide background for a larger evaluation of the program. In accordance with the original scope of the project, the review is limited to literature specifically related to the 1915(c) waiver program.

This review also primarily focuses on two categories of programs that constitute the majority of recipients and expenditures: (1) programs serving aged individuals and individuals under age 65 with physical disabilities (A/D); and (2) programs serving individuals with mental retardation or developmental disabilities (MR/DD).

The document addresses the following six areas:

1. History of the waiver program;
2. Current program characteristics;
3. The role of care management and consumer direction;
4. Issues related to quality of care and life in HCBS waivers;
5. Cost control mechanisms; and
6. Evaluations of cost savings associated with the waiver program.

I. HISTORY OF THE 1915(C) HOME AND COMMUNITY BASED SERVICES (HCBS) WAIVER PROGRAM

A. Medicaid-Funded Long-Term Care Prior to the 1915(c) Waivers

From its origin in 1965 to the present, the Medicaid program has successively expanded the types of long-term care covered and the settings in which they can be provided. Initially, Medicaid provided comprehensive long-term care (LTC) in institutional settings only. States could also provide some home health care services at their option. Coverage of home health care became mandatory in 1967. Medicaid does not tie eligibility for home health care to hospitalization or the need for skilled care, as does Medicare. Despite this flexibility, most states restricted use of home health care particularly for services other than skilled nursing (Benjamin, 1993).

Beginning in 1975, states could provide personal care services as a part of their state plan. While this option limits states to personal care services, states have latitude in what they defined as personal care and who can provide it.

B. Authorization of the Waiver

The original legislative intent of the HCBS Waiver program was to slow the growth of Medicaid spending. Legislators believed that LTC costs could be contained if services were provided to some individuals in less expensive settings, such as at home or in the community, rather than in an institution. In order to contain costs, the legislation limited services to those who would be institutionalized if the services were not provided (Benjamin, 1993).

The waivers were authorized under Section 2176 of the Omnibus Budget Reconciliation Act (OBRA) of 1981 (PL 97-35). The program allows states to waive certain Medicaid program requirements and thereby deviate from Medicaid requirements in the following ways:

- services do not have to be provided statewide;
- states can use more liberal financial eligibility criteria; and
- designated groups can be given benefits that other groups are not eligible to receive (APHSA web-site, 1999).

C. Changes in Major Federal Government Requirements Related to the Waiver Program

Through the HCBS Waiver program, states can receive matching federal funds to provide services in the home or community. States have to meet certain requirements to receive federal funding. For example, they must apply for each specific waiver to the Secretary of the Department of Health and Human Services, and demonstrate that the program is "cost neutral" as defined by a formula developed by HCFA. Essentially, the cost neutrality test requires that the average costs with the waiver must be equal to or less than the average costs without the waiver.

Changes in populations that a waiver could target and how HCFA defined cost neutrality affected the growth of the program. Shortly after the start of the program, to meet the cost neutrality requirement, states had to demonstrate that a bed in a Medicaid-certified institution was available or would be available if a certificate of need (CON) request were filed for each waiver participant (the so-called “cold bed” requirement). In addition, states had to demonstrate that the average cost for waiver recipients was lower than the average institutional cost. This requirement was intended to prevent an increase in cost associated with individuals coming "out of the woodwork" to receive more appealing, community-based services. It also limited states’ ability to refinance HCBS that were being funded with state-only financing by shifting recipients to a waiver that was financed through Medicaid.

Benjamin (1993) reports that the initial "stringent" program requirements restricted the states' ability to create innovative programs and led to relatively few people being served by Waiver programs. Beginning in the mid-1980s, the federal government relaxed those restrictions in a number of ways:

- The Omnibus Budget Reconciliation Act of 1987 modified the cost neutrality requirement by making it less restrictive for programs that provide services to the mentally retarded and developmentally disabled (MR/DD) population. The revised regulations allowed states to compare waiver costs in the community for individuals with developmental disabilities who had resided in nursing homes to the costs that would be incurred had care been provided in an intermediate care facility (ICF/MR), which were typically more costly, but provided more appropriate services (Price, 1992).

- In 1987, the federal government began to fund waivers that provide community–based services for adults and children with HIV and AIDS as an alternative to hospitalization (Miller, 1992).

- In 1987, Congress created a new waiver option, know as the 1915(d). Unlike the 1915(c) waiver, this waiver was not subject to the "cold bed" requirement. Instead, annual increases in total spending were tied to growth of size of the population age 65 and older. Oregon was the only state to use the 1915(d) Waiver (Price, 1992). In 1994, the year HCFA simplified the cost neutrality formula, Oregon converted their 1915(d) waiver back to a 1915(c) waiver. The State decided that the spending growth limitations placed by the (d) waiver, which were tied to growth of the age 65 and older population, were more restrictive than those for the (c) waiver, which were tied to growth of per capita institutional costs, once the "cold bed" requirement was removed.

- In a 1990 amendment to the Omnibus Budget Reconciliation Act, Congress allowed states to use ICF/MR facilities that were terminated from participating in Medicaid for cost comparisons (Price, 1992).

HCFA simplified the cost neutrality formula in 1994 when it removed the "cold bed" requirement and simplified the cost neutrality formula and reporting requirements. The removal of this requirement provided states with much more flexibility in determining how much individual waiver programs would grow. Currently, states must only demonstrate that on average, spending for those receiving waiver services would not exceed the average amount for those in institutions.

D. Legal Challenges and Decisions Related to the Waiver Program

In addition to the commitment of certain states to reduce their institutional populations, legal challenges and decisions have also affected the growth of waiver programs, especially those serving individuals with MR/DD. Class action court decisions and settlements have compelled a commitment to develop community services along with substantial reforms within existing institutions. The reforms of institutional care became a factor in further deinstitutionalization because they increased institutional care costs (e.g., requiring more staff, etc.). (Lakin and Hayden, 1999).[1]

Many of the most influential of these class action suits filed were heard in the first half of the 1970s (Halderman v. Pennhurst State School & Hospital, 1974; Horacek v. Exon, 1972; New York Arc v. Carey, 1972; Ricci v. Okin, 1972; Welsch v. Likins, 1972; Wyatt v. Stickney, 1971). These cases consistently concluded that civil rights of individuals with MR/DD in state institutions were being violated and that these individuals were being forced to live in inhumane conditions where physical, emotional, and sexual abuse, and physical and medical neglect were the common experience. Similar suits in other states soon followed these initial cases.

In 1981, the U.S. Supreme Court ruled in Youngberg v. Romeo that residents of state-operated institutions had constitutionally protected rights to reasonably safe conditions of confinement, freedom from unreasonable bodily restraints, and such minimally adequate training as reasonably might be required by these interests. However, the implications of Youngberg v. Romeo were limited in application and generalizability and did not affirm a right to live in the community. In the 1980s, class action suits involving state institutions, virtually all of which were now Medicaid certified, continued. The number of cases filed between 1981 to 1990 (32) was actually greater than in the previous decade (21). The claims of abuse, neglect, inhumane living conditions, and lack of access to beneficial treatment continued to be upheld.

Class action suits have continued in the 1990s. One of the interesting and important features in this third decade of class action litigation is that self-advocacy organizations have often been the plaintiffs (e.g., People First of Tennessee v. Arlington Developmental Center, 1991; People First of Tennessee v. Clover Bottom Developmental Center, 1995; People First of Washington v. Rainier Residential Habilitation Center, 1996), co-plaintiffs (e.g., Coffelt v. DDS, 1991; Messier v. Southbury Training School, 1994), and plaintiff-intervenors (United States v. Tennessee, 1992). The allegations in these suits have been similar to the allegations brought forth in the earliest litigation of the 1970s; they have cited the same types of physical, emotional, and sexual abuse; physical and medical neglect; inhumane living conditions; and civil rights violations that were cited in earlier suits. Lakin has argued that these cases in their individual states and at the national level continue to establish a perspective that regardless of how many regulations are created and how they are enforced, it is extremely difficult for institutions to avoid violation of people’s basic rights (Lakin and Hayden, 1999), at least for the population with MR/DD. This has created pressure to serve individuals in the community rather than to try to reform institutions.

The 1990 Americans with Disabilities Act (ADA) had several important implications for the Waiver program. It required that states provide services in the "most integrated setting appropriate," and several recent rulings have upheld the rights of people with disabilities to receive care at home or in the

[1]Subsequent paragraphs on the legal aspects of the waiver program are also from Lakin and Hayden (1999), an unpublished paper written under the same contract as this report.

community. In Helen L. v. DiDario (1995), the United States Court of Appeals for the Third Circuit found a state in violation of the ADA for failure to provide state-funded attendant care, which would have enabled a paralyzed woman to live in her own home rather than in a nursing facility (HCFA, 1998).

In Olmstead vs. L.C. (1999), the Supreme Court recently upheld a lower court ruling that, to avoid violating the ADA, requires states to place people with mental disabilities in community settings instead of institutions if community placement is appropriate, the transfer to the community is not opposed by the individual in question, and placement can be accommodated given the resources available (Carelli, 1999). The Olmstead decision could affect states' provision of HCBS by forcing them to allocate the resources necessary to serve that population in the community. However, the law also indicates that states can resist modifications that would fundamentally alter the nature of their services and programs. States must also consider the total mental health budget in planning community services (Olmstead vs. L.C. – October Term 1998, N. 98-536). This ruling has particular relevance to the waiver program because it requires that states that maintain waiting lists make a good effort to move people to community programs at a reasonable pace (Davis, et.al., 2000).

In response to Olmstead, HCFA sent a letter dated January 14, 2000 to all Medicaid directors. In this letter, the Administration expresses support for Olmstead:

> ...no one should have to live in an institution or a nursing home if they can live in the community with the right support. Our goal is to integrate people with disabilities into the social mainstream, promote equality of opportunity and maximize individual choice.[2]

The letter recommended that states develop comprehensive plans to "strengthen community service systems and serve people with disabilities in the most integrated setting appropriate to their needs."

II. GROWTH OF THE WAIVER PROGRAM

For analysis purposes, it is difficult to consider the aged/disabled, MR/DD and other target population waivers as a single "program". While they face some common challenges, such as the coordination of services, monitoring service quality, increasing consumer control of resources and service purchasing, there are vast differences both across and within the two populations in terms of size of the programs, spirit, level of support, commitment, prevailing issues, goals and even the non-federal administrative entities that manage them.

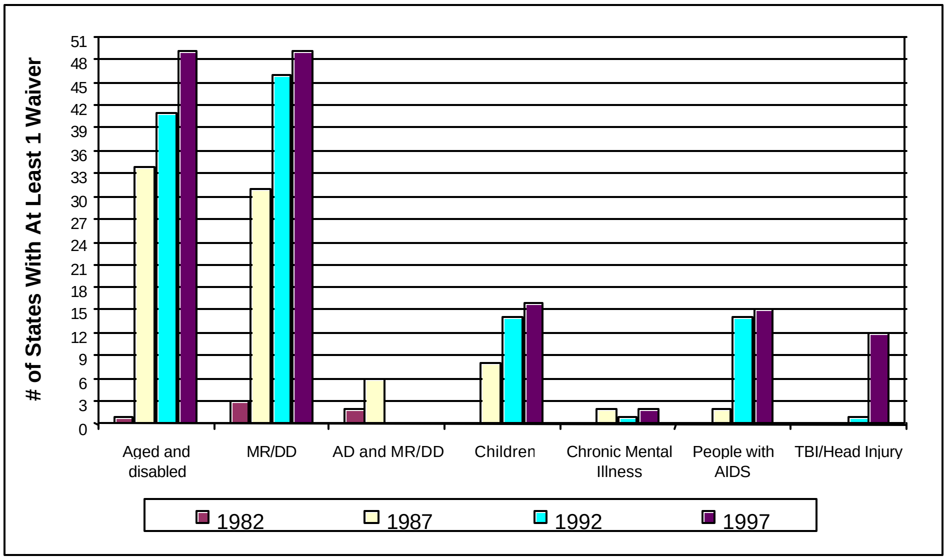
[2] Letter to state Medicaid directors dated January 14, 2000 sent by Timothy M. Westmoreland, Director Center for Medicaid and State Operations, HCFA.

A. Growth of States Operating Programs

Since the start of the Waiver program the number of states with at least one waiver program has expanded from one state to all states (***Exhibit 1***). In 1982, only six states had waivers. By 1999, every state except Arizona (which provides LTC services through a 1115 waiver) had at least one MR/DD waiver and one waiver targeted towards the aged and/or under 65 with physical disabilities populations.

Exhibit 1

Number of States with at Least One Waiver by Target Population, 1982-1997



Source: The Lewin Group analysis of HCFA Form 372 data provided by Charlene Harrington, UCSF and Miller, N.A. (1992). Medicaid 2176 Home and Community-Based Care waivers: The First Ten Years. Health Affairs, 11:4, 162-171.

The populations served through the waiver program have also changed since the implementation of the program. Originally, the waiver program was composed exclusively of A/D, MR/DD, and combined A/D and MR/DD programs. As changes in regulations have allowed the waivers to serve other populations, including children with special health needs, adults and children with AIDS, and people with traumatic brain injuries (TBI), the number of states implementing such programs has increased. The number of waiver programs serving people with chronic mental illness has not increased, and Price (1992) points out that this is probably due to difficulties in showing cost effectiveness because Medicaid does not cover institutional costs for non-elderly adults with mental illnesses.[3] The mental health waivers currently operating serve children.

[3] Elderly with chronic mental illness may be receiving services under an aged only or A/D waiver if their mental illness is secondary to age or disability

B. HCBS Waiver Program Expenditures and Recipients

The current understanding of cost and use patterns for the 1915(c) waiver program is limited by the availability of data. Publicly available data includes HCFA's Forms 64, 2082, and 372. Publicly available data from Form 64 provides expenditure data for 1915(c) waivers by state. Unfortunately, this data is not delineated by target population, nor does it provide information about the number of recipients served. While Form 2082 provides information about recipients as well as expenditures, it does not separate expenditures for HCBS waivers from the broader category of home health and HCBS waivers that may also be recorded under "other" services. Form 372 contains expenditure and recipient data for each waiver program. HCFA does not currently gather these reports from the regional offices and make them publicly available. We were able to conduct analysis on 372 forms for the years 1992-1997 collected and coded by Charlene Harrington and colleagues at the University of California, San Francisco (USCF). However, there were inconsistencies between expenditures on these forms and data from Form 64. In our analyses, we assumed Form 64 data would be more reliable because it determines payment.

1. Relationship of Waiver Spending to Other Medicaid Long-Term Care Spending

While institutional care continues to account for the bulk of Medicaid long-term care spending, the proportion accounted for by HCBS grew from 16 percent in 1992 to 26 percent in 1999 (***Exhibit 2***).[4] The 1915(c) waiver program is increasingly dominating Medicaid HCBS spending; waivers grew from two-fifths of Medicaid HCBS spending in 1992 to almost two-thirds in 1999. Personal Care Option spending accounted for 22 percent of Medicaid spending in 1999 and home health accounted for approximately 14 percent.

For MR/DD programs, the HCBS Waiver program has become the primary funding stream for a strong pre-existing initiative to deinstitutionalize and develop community alternatives. Between 1992 and 1997 the number of MR/DD HCBS waiver recipients grew at an annual rate of nearly 30 percent. The commitment to deinstitutionalize has allowed HCBS to be viewed as the primary funding stream for community services rather than as a separate program serving a limited number of slots. That funding stream has been used to match state funds with federal and to refinance previously state-only funded community services with federal funds to free up state dollars to leverage additional federal resources for even more community services, as well as for other purposes. For these reasons, it is difficult to separate HCBS Waiver programs for people with MR/DD from community services for persons with MR/DD in general.

In contrast to the MR/DD HCBS waivers, HCBS waivers for the aged and disabled population (A/D) play a smaller role in providing care to the Medicaid eligible population than institutional care. In 1997, the number of Medicaid A/D HCBS waiver recipients was approximately one-fifth the number of

[4] The Lewin Group analyses of HCFA 64 data supplied by Brian Burwell at MEDSTAT.

Medicaid nursing facility residents. The growth of recipients has also been slower in the A/D waivers; compared to the 30 percent figure for MR/DD programs, population adjusted recipients for A/D waivers grew at an annual rate of approximately ten percent between 1992 and 1997.[5]

Per recipient waiver spending fails to capture actual spending on waiver recipients because it only accounts for a portion of their expenditures. HCBS waiver recipients typically have some of their care, most notably acute care, home health, personal care, targeted case management and adult day care, funded from the regular Medicaid program. Information sent to Lewin by the states confirmed that states generally fund acute and skilled home health services through the general Medicaid program for waiver recipients. There was substantial variation for funding of personal care and case management with some states funding these services through the waiver, while others funded them through the Personal Care Option and Targeted Case Management.

2. Growth of Expenditures for the Waiver Program

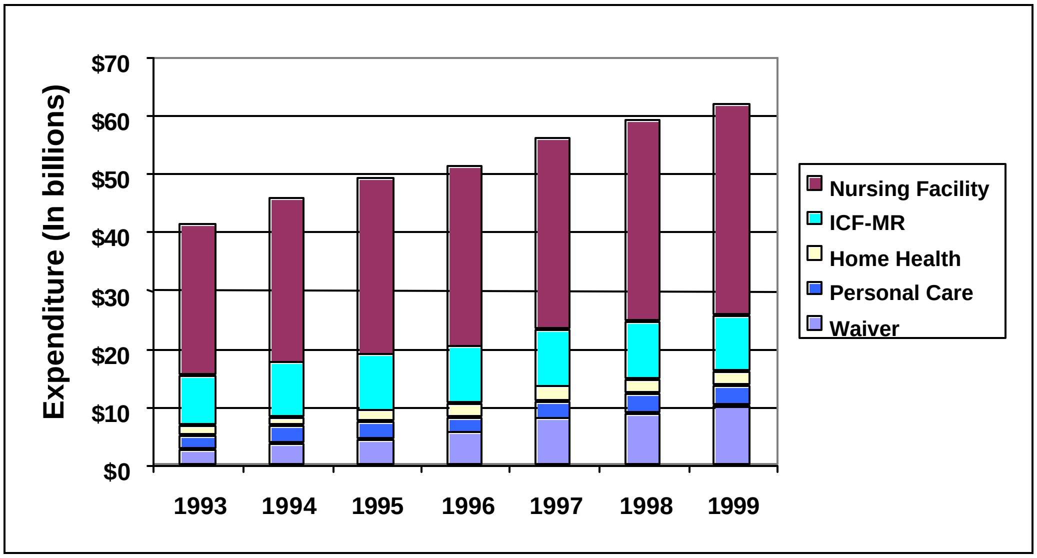
Spending for the waiver program has increased significantly since the program started. In 1985, three years after the start of the program, total waiver expenditures were $290 million (Miller, 1992). By 1999, spending had increased to almost $10.4 billion.[6] Waiver spending has been increasing at a much faster rate than other types of Medicaid long-term care spending (***Exhibit 2***). Between 1993 and 1999, waiver spending increased at an annual rate of almost 25 percent per year, while other categories of Medicaid long-term care grew at annualized rates of between two and eight percent.

[5] This figure represents per capita growth for individuals ages 85 and older using 372 data from Charlene Harrington and Census Bureau data.

[6] Based on HCFA form 64 data supplied by Brian Burwell.

Exhibit 2

Growth of Medicaid Long Term Care Expenditures: FY 1993 –1999 (in billions of nominal dollars)

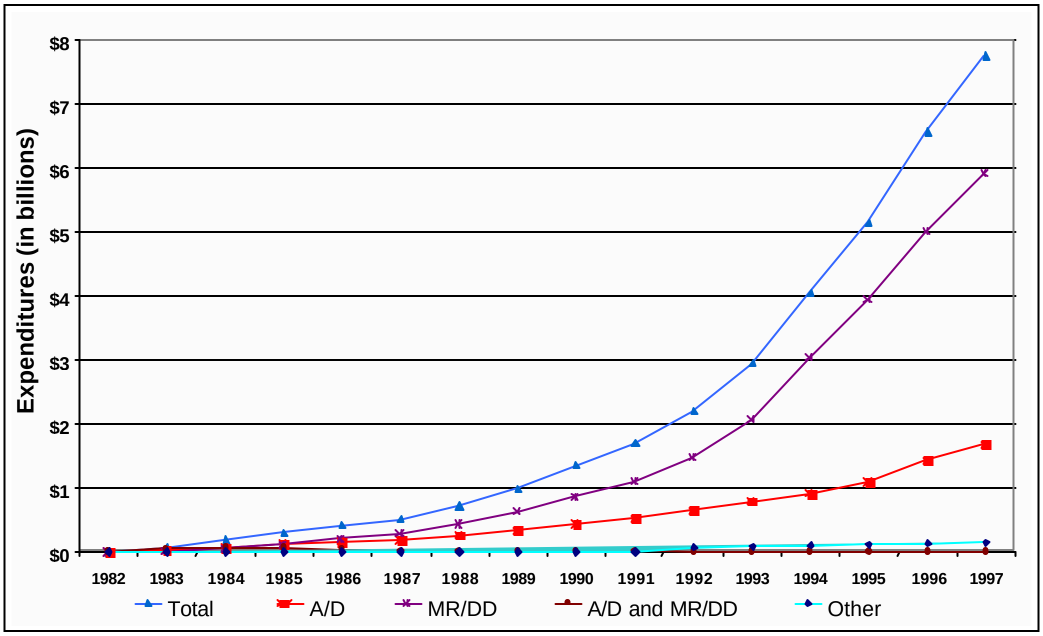


Source: The Lewin Group analyses of HCFA 64 data supplied by Brian Burwell at MEDSTAT.

Expenditures for some types of waivers have increased more rapidly than for others **(*Exhibit 3*)**. MR/DD waiver spending grew the most rapidly, from $1.5 billion in 1992 to $5.9 billion in 1997. The expenditures for MR/DD waivers accounted for three-quarters of the total amount spent on waivers in 1997. Expenditures for A/D waivers have also increased considerably, growing from $0.6 billion in 1992 to $1.7 billion in 1997.

Exhibit 3

1915(c) HCBS Waiver Expenditures by Population: 1982 –1997



Source: The Lewin Group analysis of HCFA Form 372 data provided by Charlene Harrington, UCSF and Miller, N.A. (1992). Medicaid 2176 Home and Community-Based Care waivers: The First Ten Years. Health Affairs, 11:4, 162-171.

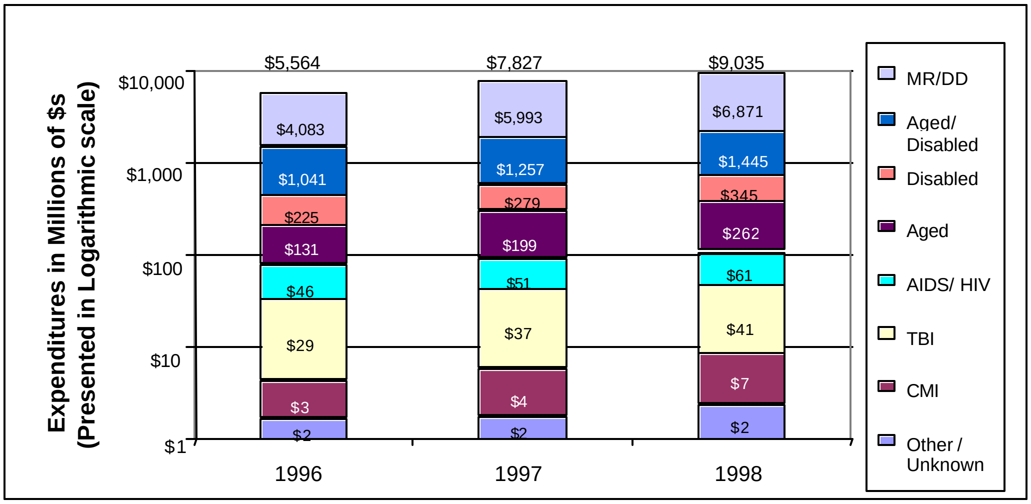
We were able to obtain data on waiver expenditures by target population from analyses that John Drabek at the Office of the Assistant Secretary for Planning and Evaluation (ASPE) calculated from quarterly HCFA 64 Forms ***(Exhibit 4)***.[7] These data were roughly consistent with the 372 data; 372 expenditures for all waivers were 18 percent higher than quarterly 64 data in 1996, but two percent lower in 1997. However, state-level comparisons revealed some sharp inconsistencies for certain programs.

Based on estimates from the quarterly HCFA 64 data, MR/DD waivers accounted for approximately three-fourths of all waiver spending in 1996-98. Waivers serving the aged and/or disabled accounted for most of the remaining expenditures. Spending on other waivers accounted for a little more than one percent of expenditures between 1996 and 1998.

[7] This data included a break down of MR/DD versus non-MR/DD spending. The majority of non-MR/DD spending is assumed to go to the A/D population.

Exhibit 4

Medicaid HCBS Waiver Expenditures by Target Population (1996-1998)



Source: Quarterly HCFA 64 data from John Drabek, ASPE

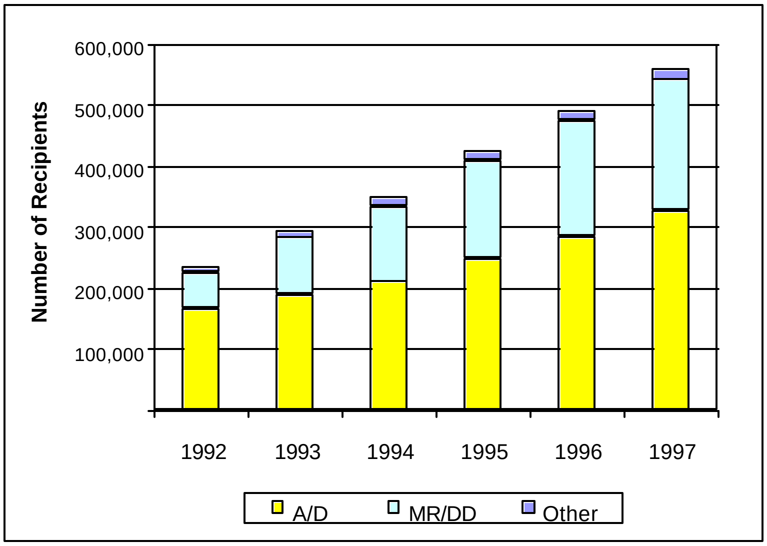
3. Growth of the Number of Recipients

The number of recipients of waiver services has increased dramatically in recent years ***(Exhibit 5)***. From 1992 to 1997, the total number of waiver recipients served in a given year more than doubled, increasing from 234,470 to 559,903 people.[8] Nearly twice as many people received A/D waiver services in 1997 as in 1992 (326,020 and 166,541 people respectively). The number of MR/DD waiver recipients showed the greatest increase, nearly quadrupling from 58,190 people in 1992 to 215,812 people in 1997.

[8] The Lewin Group Analysis of HCFA form 372 data supplied by Charlene Harrington at the University of California, San Francisco (UCSF).

Exhibit 5

1915(c) HCBS Waiver Recipients by Population



Source: The Lewin Group analysis of HCFA Form 372 data provided by Charlene Harrington, UCSF and Miller, N.A. (1992). Medicaid 2176 Home and Community-Based Care waivers: The First Ten Years. Health Affairs, 11:4, 162-171.

4. MR/DD and A/D Waiver Per Capita Expenditures and Recipients

Under a different contract with HCFA, Charlene Harrington and her colleagues at UCSF coded, cleaned, and analyzed information from 372 Forms for 1992 to 1997. These forms include both recipient and expenditure data for each individual waiver. They also include information about expenditures by types of services. MR/DD and A/D waivers are discussed below because they constitute the majority of recipients and expenditures.

Lewin's analysis of these data indicated that states differ widely in terms of the following statistics:

- Per capita expenditures;
- Per recipient expenditures; and
- Per capita recipients.

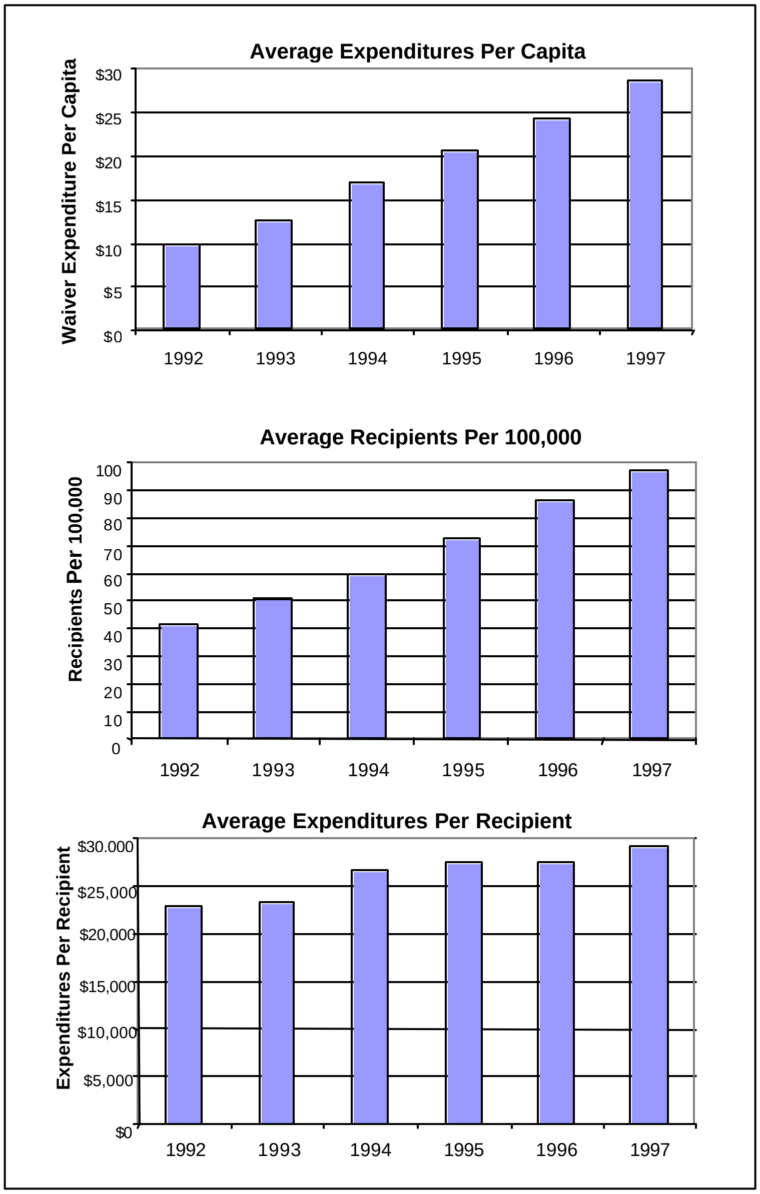
a. Per Capita Expenditures and Recipients: MR/DD

Different factors account for the increases in spending for MR/DD waivers and A/D waivers. For the MR/DD waiver programs, most of the growth in program expenditures is due to the large increase in the number of waiver recipients, not the increase in per recipient spending. The increase in average per recipient spending has been moderate; the average per recipient costs grew almost 30 percent from $22,864 in 1992 to $29,120 in 1997. In contrast, the number of average MR/DD recipients per 100,000 population under age 65 rose 130 percent from 41.3 in 1992 to 97.0 in 1997 ***(Exhibit 6).***

We observed substantial variation across the states. Commitment to HCBS, measured in terms of number of people served or amount of dollars spent, varied dramatically among the states. Average expenditures per recipient for MR/DD waivers in 1997 ranged from $2,575 to $69,634. Some of the variation may be due to the fact that services such as case management and personal care may not be funded through the waiver in some states.

Exhibit 6

Average State Expenditures, Recipients Per 100,000, and Average Expenditure per Recipient for 1915 (c) MR/DD Waivers: 1992-1997



Source: The Lewin Group analysis of HCFA Form 372 data provided by Charlene Harrington, UCSF and Census Bureau data.

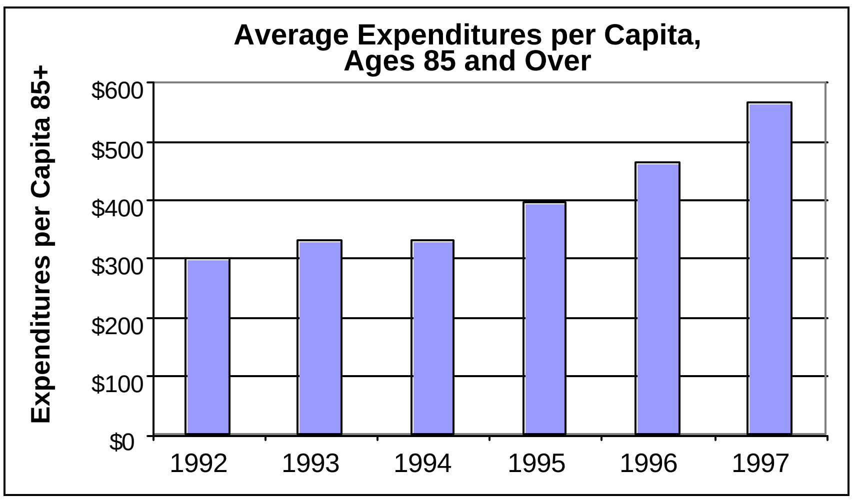
b. Per Capita Expenditures and Recipients: A/D

The average per capita expenditures for A/D waivers doubled from $229 in 1992 to $565 in 1997 ***(Exhibit 7)***. For A/D waivers, the increase in average number of recipients per 100 individuals ages 85 and older grew from 6.6 in 1992 to 9.8 in 1997, a slower rate of increase than for MR/DD waivers, which more than doubled. The average per recipient costs grew from $4,530 in 1992 to $5,989 in 1997 similar to the 30 percent increase in the MR/DD waiver recipient cost.

The aged/disabled waivers also showed substantial variation across states. The range of expenditures per recipient in 1997 was from $1,153 to $14,287.

Exhibit 7

Average State Expenditure, Recipient and Expenditure per Recipient for 1915 (c) Aged/Disabled Waivers: 1992 - 1997



Source: The Lewin Group analysis of HCFA Form 372 data provided by Charlene Harrington, UCSF and Miller, N.A. (1992). Medicaid 2176 Home and Community-Based Care waivers: The First Ten Years. Health Affairs, 11:4, 162-171.

III. PROFILE OF CURRENT HCBS WAIVER PROGRAMS

The following discussion centers on the eligibility requirements and types of services provided in general and for A/D and MR/DD waivers specifically. Information is based on previous studies and Lewin's analysis of initial or renewal waiver application forms submitted by states and on file in 1999.

A. Eligibility

Two primary criteria determine eligibility for 1915(c) waiver programs: (1) financial eligibility for Medicaid; and (2) functional eligibility for the services provided, which is generally tied to eligibility for institutional care. Recipients of waiver services must meet both sets of criteria.

Prior to the creation of the HCBS waiver program, financial eligibility requirements for Medicaid were less stringent for institutional services than for home-based services, which made it easier for people to enter institutions rather than to receive care in the home. The waiver program helped to correct this institutional bias by allowing states to set financial eligibility limits for income as much as 300 percent of the federal Supplemental Security Income (SSI) benefits, generally the same level used for nursing facilities. In 1997, 38 states had adopted financial eligibility criteria that were more lenient than for general Medicaid for at least one of their waiver programs (Miller et. al., 1999).

The functional eligibility criteria for waiver services vary widely from state to state and vary by waiver target population within a given state. In many states, the functional eligibility criteria for waiver services are the same as those for entrance into a nursing facility. In other states, such as Washington, different criteria--including the need for assistance with a particular number of ADLs or IADLs--are used. A study of aged and disabled waiver program eligibility criteria (O'Keeffe, 1996) found three major types of eligibility criteria used by states. Among the 42 states that participated in the study, six used a scored assessment instrument to determine eligibility, 19 states required that applicants have a minimum number of impairments or long-term care needs, and 17 states provided assessors with guidelines to assist them in determining eligibility. The latter type of eligibility determination is the most subjective and relies heavily upon the assessor's judgement, while the former types are generally more objective.

The eligibility of persons with "mental retardation and related conditions" for Medicaid ICF-MR and, thereby, alternative HCBS long-term care services, is generally linked to actual or potential eligibility for cash assistance under federal welfare programs. In the case of ICF-MR and HCBS-MR eligibility, the eligibility standard is that of the Supplemental Security Income (SSI) program. SSI eligibility for persons with "mental retardation and related conditions" who are under 65 years and who demonstrate financial need by both income and asset tests is determined from condition listings and associated definitions adopted by the Social Security Administration. SSI classifies individuals as having mental retardation if they have an IQ of 59 or less, or persons who have an IQ of 60-69 who have physical and mental impairments that impose significant work-related limitations. Persons with "related conditions" are eligible for ICF-MR and HCBS when they have a severe, chronic disability that is attributable to cerebral palsy, epilepsy or any other condition, other than mental illness. That condition must be:

1) closely related to mental retardation in that it impairs intellectual functioning or adaptive behavior so that services like those needed by persons with mental retardation are required;

2) manifested before age 22;

3) likely to continue indefinitely; and

4) resulting in substantial functional limitation in three or more of the following areas:

    - self-care,

    - understanding and use of language,

    - learning, mobility,

- self-direction, and
- capacity for independent living.

B. Services

One of the unique features of the Waiver program is the broad variety of services that may be provided as a part of the program, including non-medical services such as homemaker services and habilitation. Services that at least some states offer include the following:

1. Adult day care - Daytime, community-based program for functionally impaired adults that provides a variety of health, nutrition, social, and related services in a protective setting to those who are otherwise being cared for by family members. Its purpose is to enable individuals to remain at home and in the community and to encourage family members to care for them by providing relief from the burden of constant care.

2. Adult day habilitation services – Day program usually serving individuals with MR/DD, that teach skills such as cooking, recreation, and work skills. The individual may work part of the day with other individuals with disabilities in assembly and production work for piece rate wages or below minimum wages (Work Activities Center). In some sites, the recipient attends a center with peers learning non-vocational or pre-vocational skills.

3. Adult day health services – Adult day care setting which provides more health-related services.

4. Assistive technology – A range of equipment, machinery and devices that share the purpose of assisting or augmenting the capabilities of individuals with disabilities in almost every area of daily community life, including mobility, independence in activities of daily life, communication, employment learning and so forth. Specialized examples include wheelchairs and ramps, and electronic and printed picture/icon communication devices, but also can include tape recorders and tapes for messages, materials, instructions and so forth normally presented on paper, special large or punch switches available at a local electronics store, level door handles (as opposed to knobs) that are available at any hardware store, and telephones with single function keys for dialing certain numbers that are available at most department stores.

5. Adaptive equipment - Physical and/or mechanical modifications to the home, vehicle or the recipient's personal environment.

6. Case management - Services which assist individuals access needed medical, social, educational, and other services.

7. Personal care attendant – Services such as, help balancing a checkbook, grocery shopping, developing a budget, paying bills, etc.

8. Habilitation services - Services designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in

home and community based settings; and includes prevocational, educational, and supported employment.

9. Homemaker services - Assistance with general household activities and ongoing monitoring of the well being of the individual.

10. Home health aide - Health care professional who assists with specific health problems.

11. Nursing care services - Services provided by or under the direction of a registered nurse.

12. Personal care services - Direct supervision and assistance in daily living skills and activities (e.g., assisting the individual with bathing and grooming).

13. Respite care - Short-term supervision, assistance, and care provided due to the temporary absence or need for relief of recipient's primary caregivers. This may include overnight, in-home or out-of-home services.

14. Training for the family in managing the individual.

15. Day treatment or other partial hospitalization, psycho-social rehabilitation services and clinical services for people with a mental illness.

16. Vocational services - Supported employment, pre-vocational education, and other services not covered by other sources.

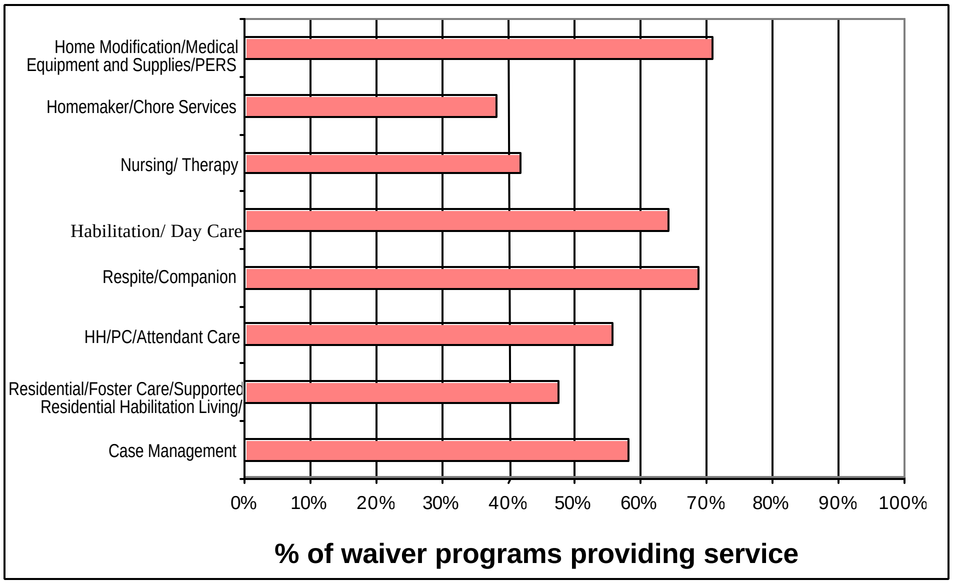
In addition, HCFA may approve other home and community-based services (other than room and board) that a state requests to cover.

Exhibits 8-12 display the types of services that waiver programs targeting different populations are providing. In these exhibits, the waiver is the unit of analysis rather than the state; some states have more than one waiver for a particular population. This information is based on what states reported in their Waiver Application forms and may not represent the full range of services recipients receive from many programs. In particular, the provision of case management and personal care may be underrepresented because some states fund these services under the target case management and personal care options of the regular Medicaid program. In addition, some states may provide case management, but may classify it as part of their administrative costs.

Exhibit 8 shows that home modifications, specialized medical equipment or personal emergency response systems (PERS) are the most commonly offered services among all waivers. Respite or companion care was the second most common service followed by habilitation or day care. Case management was listed as one of the services offered by more than half of the waiver programs. As discussed earlier, the low percentage of programs offering case management is probably misleading.

Exhibit 8

Percentage of Medicaid HCBS by Types of Services Offered: All Waivers



Source: The Lewin Group analysis of Waiver Application Forms provided in 1999.

Exhibits 9 through 11 present the types of services offered through the waivers targeted towards the aged and/or physical disability populations.

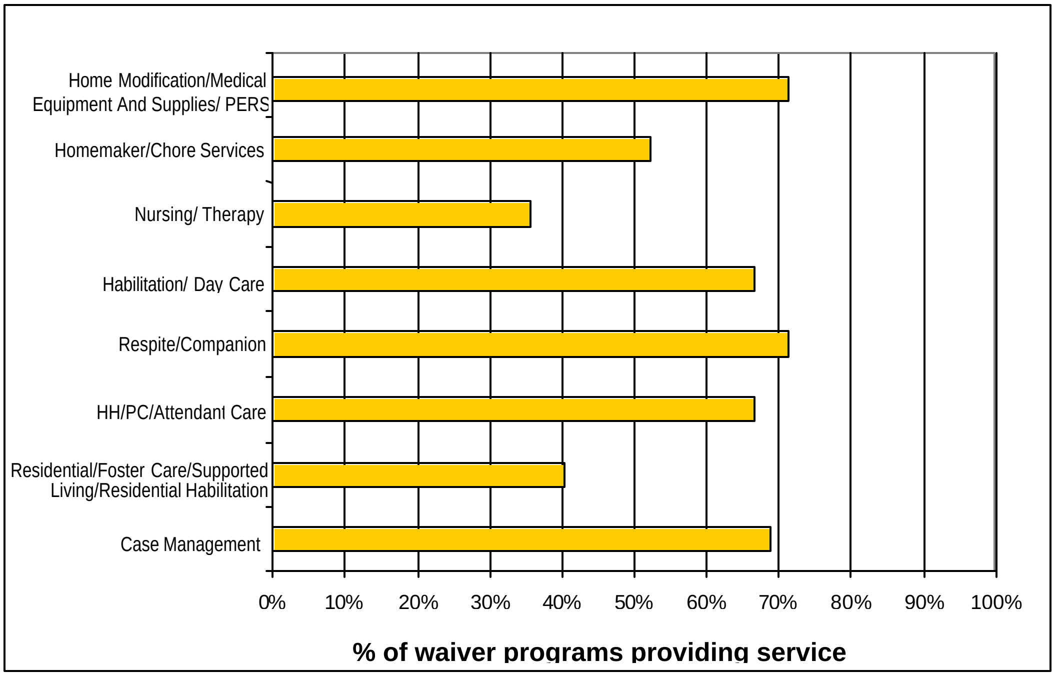
Exhibit 9 shows that waivers targeted at both the elderly and younger individuals with physical disabilities were similar to the pattern presented for all waivers in ***Exhibit 8***. However, there are some suggestive patterns for the waivers targeting either the aged or physical disability populations.

States may be using waivers targeted to only the elderly to fund services beyond personal care that are not funded in other ways through Medicaid. ***Exhibit 10*** shows that these waivers are most likely to fund home modifications, PERS, homemaker and chore services, day care, and respite or companion care than the typical waiver or waivers targeted to both aged/disability. In contrast, a relatively low percentage of these aged only waivers offer personal care or attendant care. States may believe that personal care and home health funded through the regular Medicaid program may meet this population's need for hands-on care. Thus, they use the waiver to provide other types of services.

Surprisingly, waivers targeted towards the physically disabled are even less likely to offer a range of services other than case management or personal/attendant care than aged or A/D waivers (***Exhibit 11***). They are slightly less likely to offer attendant/personal care and case management than the A/D waivers. The majority of these waivers not offering personal care or attendant care offer case management and little else, suggesting that these waivers may serve as mechanism for providing case management to personal care that is funded elsewhere.

Exhibit 9

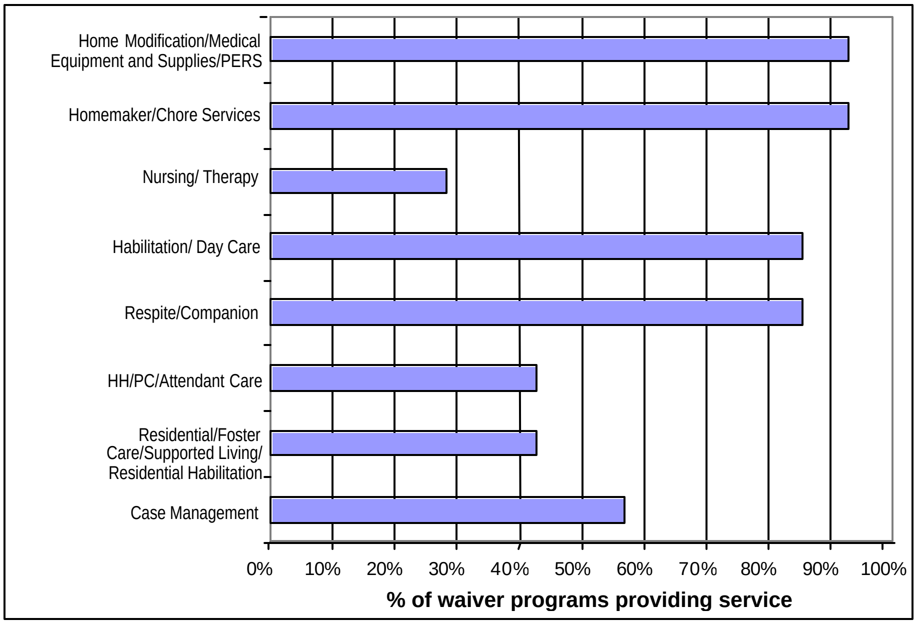
Percentage of Medicaid HCBS by Types of Services Offered: Aged/Disabled Waivers



Source: The Lewin Group analysis of Waiver Application Forms provided in 1999.

Exhibit 10

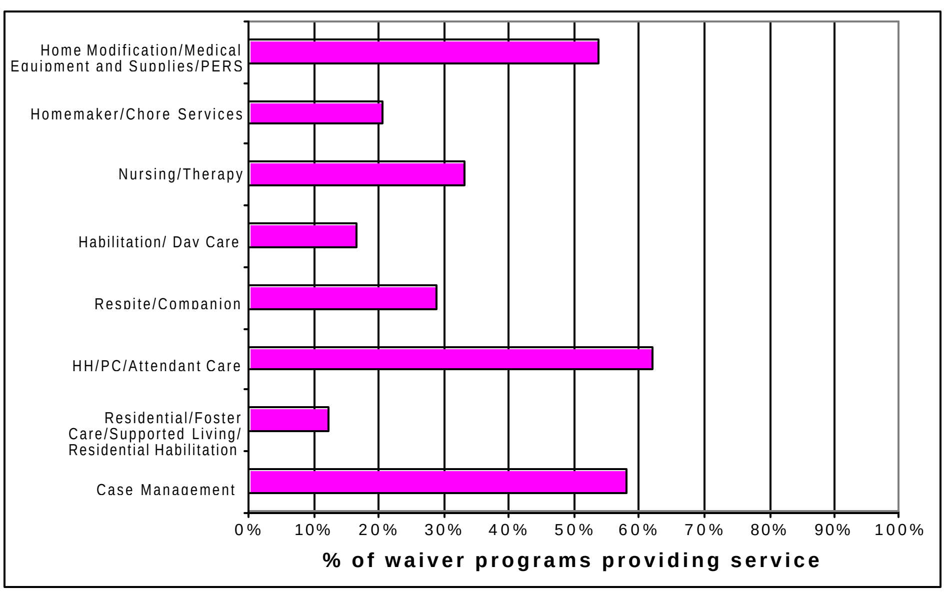
Percentage of Medicaid HCBS by Types of Services Offered: Aged Waivers



Source: The Lewin Group analysis of Waiver Application Forms provided in 1999.

Exhibit 11

Percentage of Medicaid HCBS by Types of Services Offered: Disabled/Physically Disabled Waivers



Source: The Lewin Group analysis of Waiver Application Forms provided in 1999.

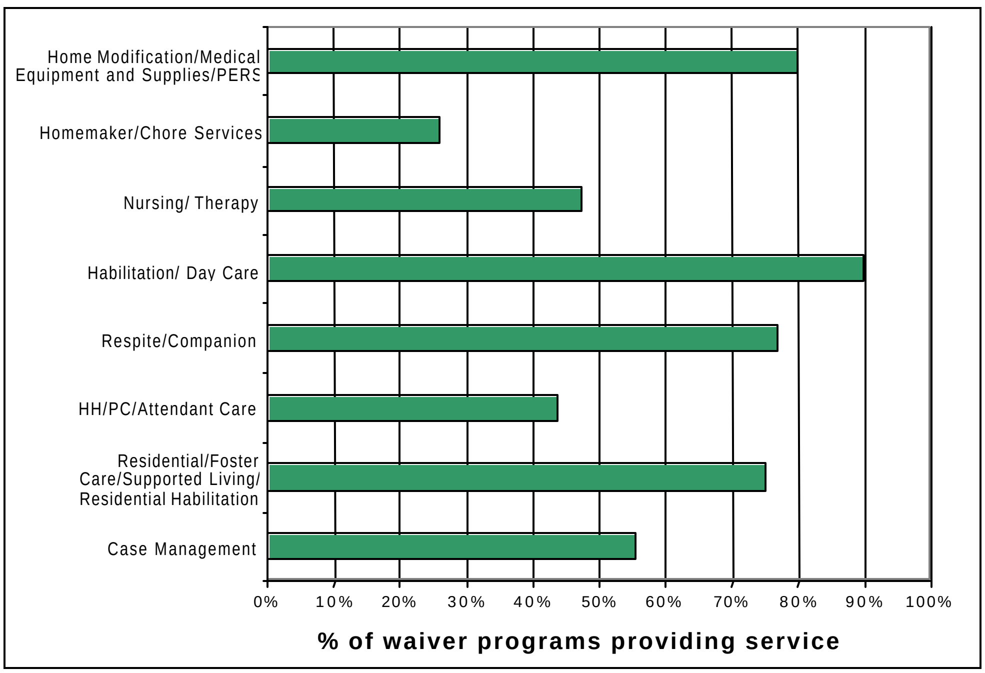
More than 60 percent of MR/DD waivers reported offering the following services:

- Habilitation
- Day habilitation
- Residential habilitation
- Respite care

More than half of the programs reported funding case management through the waiver, though this service may also be funded through targeted case management and as administration. (see ***Exhibit 12***).

Exhibit 12

Percentage of Medicaid HCBS by Types of Services Offered: MR/DD Waivers



Source: The Lewin Group analysis of Waiver Application Forms provided in 1999.

Exhibit 13 shows the number of waivers by population that offer reimbursement for family members providing personal care. A majority of the waivers that offer personal care through the waiver will pay family members. However, because the majority of waivers did not offer personal care, only approximately ¼ of all waivers for which we had data offered reimbursement for family members.

Exhibit 13

Waivers that Reimburse Family Members[9] for Providing Personal Care

Waiver	Reimbursement	No Reimbursement	No PCS through Waiver	Missing Data[10]
Aged	3	2	9	4
Aged/Disabled	11	12	18	6
AIDS/ARC	5	5	3	3
Children(Special Care)	0	0	13	2
Disabled/ Physically Disabled	6	4	14	3
Mental Health	1	0	2	0
MR/DD	14	8	39	15
Other	0	0	1	3
TBI/Brain Injury	6	2	4	5
Grand Total	46	33	103	41

Source: The Lewin Group analysis of Waiver Application Forms collected in 1999.

IV. THE ROLE OF CARE MANAGEMENT AND CONSUMER DIRECTION

Care management and consumer direction play important roles in determining what waiver services are provided, who provides them, what setting they are provided in, and how frequently they are provided. Traditionally, case or care managers have coordinated and monitored the provision of LTC services. Increasingly, consumer direction allows clients to take an active role in managing their own care, on a number of different levels.

A. Case/Care Management

Although all clients of 1915(c) Waiver programs must be assessed and have individual care plans, states are not required to provide case managers. Although not required, most states provide case managers. A study by Folkemer (1994) found that out of 46 long-term care programs (43 of these were 1915(c) Waivers), 41 (89 percent) reported that case management was provided by the program. A 1991 study of HCBS for persons with MR/DD found that among the 36 states reporting, 92 percent of states reported that all service recipients received case management (Prouty and Lakin, 1991).[11]

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9 Parents and spouses are not allowed to receive reimbursements for providing PCS.

10 Missing data are due to: (1) not receiving the waiver application form; or (2) the version of the waiver application submitted did not include the item about family member reimbursement.

11 These studies are not necessarily inconsistent with data from the waiver application forms. Some of the states not reporting funding case management may in fact provide the service in one of the following ways: (1) case management is funded under the Targeted Case Management Option; (2) case management is treated as an administrative expense rather than a service; or (3) case management is done by a provider, such as a home health agency, and is considered part of that service.

Some states use only state agency personnel as case management providers, other states contract these services to outside providers, and still others use a combination of the two. For example, Oregon uses a combination of state agency personnel and Area Agencies on Aging (AAAs) to provide case management; Connecticut relies on non-state agencies to provide these services. Prouty and Lakin (1991) also found that among the 36 MR/DD waiver programs reporting, case management was provided by state government agencies in 18 states (50 percent), non-government agencies in 11 states (31 percent), local government agencies in four states (11 percent), and a combination of government and non-government agencies in three states (eight percent).

Case managers play an important role in coordinating and monitoring long-term care services provided through the Waiver program. According to a GAO report on case management (1993), case managers serve five "core" functions within the context of long-term care: assessing client needs, developing a care plan, arranging services, monitoring clients, and periodically reassessing needs. These "core" functions determine who receives what services.

Assessment. All waiver programs have to assess clients to determine if they meet the functional eligibility criteria. In addition, by assessing possible clients, case management should help to ensure that funds are allocated to those with the greatest need. Many Waiver programs use standardized assessment tools to help case managers better determine if potential clients are eligible for the program. The use of a standard assessment tool allows case managers to apply eligibility criteria more consistently. The detailed information collected may also provide the groundwork for the plan of care (Justice, 1993).

Care Planning. The plan of care determines clients' access to services. According to a study of HCBS programs (including 1915 (c) waivers) in four states, "in general there are no formal rules that determine which services an individual receives" (Kassner and Martin, 1996). Instead case managers develop an individualized plan of care which takes into account the clients' unmet needs as well as the current living arrangements and the amount of informal support available. Ideally, the plan is a collaboration between the case manager, the client, and when necessary, the client's family or legal guardian. All states require clients' signatures on care plans, and almost all responding to one study indicated that clients make the determination of whether they receive care in the home, in the community, or in an institution (Kassner and Martin, 1996)[12]. Prouty and Lakin (1991) found that out of 36 states that responded regarding MR/DD waivers:

- 31 states (86 percent) reported that case managers were required to participate in the development of written plans of care for recipients with MR/DD;
- 25 states (69 percent) reported that recipients themselves must participate;
- 19 states (53 percent) reported that family members must participate (when appropriate); and
- 18 states (50 percent) reported that service providers and guardians must participate in the development of the plan of care.

[12] Because institutional care is an entitlement, states cannot deny entry if the individual is eligible.

Service Arrangement. Another duty of case managers for HCBS programs is to arrange or coordinate the services that are provided to clients. In some instances, spending caps and budget restraints may limit case managers' ability to arrange for services. Some services may not be available due to costs, or may have long waiting lists. Some services may be mandated (GAO, 1993). Another study found that among 35 responding states, MR/DD program case managers filled the following roles:

- case managers arranged services for clients with MR/DD in 34 states (97 percent);
- case managers identified qualified service providers in 29 states (83 percent);
- case managers selected service providers for individual clients in 20 states (57 percent); and
- case managers contracted with service providers 14 states (40 percent) (Prouty and Lakin, 1991).

Monitoring and reassessment. Case managers must also monitor long-term care clients. The six states included in a study of case management (Justice,1993) all had established standards for monitoring and reassessing clients on a regular basis. These standards set the frequency with which case managers should contact their clients, both face-to-face and by telephone. Standards vary from state to state, but almost all require face-to-face visits at least once every six months. High caseloads may limit the ability of case managers to meet these standards.

Reassessments assure that the services provided for in the plan of care are still necessary and adequate to meet the client's changing needs. Many states use the same tool used for the initial assessment for reassessment, sometimes in an abbreviated form. Some states use a different standardized tool, and a few do not use standardized tools for reassessments (Justice, 1993). All states require a reassessment at least once every year.

B. Consumers' Ability to Direct Their Own Care

Consumer direction encompasses decision-making, personal choice, self-advocacy, self-determination, and self-expression. A fundamental aspect of consumer direction of services is consumer control over the selection of services, provider agencies and individual support providers. Initiatives under a range of demonstration projects and waiver amendments in the United States and other countries have fostered such consumer control by allowing consumers to manage and control their own service budget.

A growing body of research suggests that younger individuals, and individuals with fewer cognitive impairments have a stronger preference to control the care they receive (Flanagan, 1994; Tilly and Weiner, 2000). One study indicated that younger persons with disabilities tend to prefer high levels of consumer-direction which increases their autonomy, while elders prefer moderate to low levels of consumer direction, but prefer to have the option of choosing a family member or friend to provide care (Flanagan, 1994). Although older persons may be less likely to articulate a preference for consumer direction, many older people participate in consumer-directed programs (Tilly and Weiner, 2000), especially if these programs offer cash benefits (Desmond et al. 1998; Mahoney et al. 1998; Simon-Rusinowitz et al. 1997; Simon-Rusinowitz et al. 1998).

A paradigm shift in the views of how services for the MR/DD population should be delivered may be increasing the level of consumer direction in MR/DD programs. For persons with MR/DD, consumer/family management of budgets is only one aspect of increased forms of consumer control. Increasingly, the consumer direction movement is creating pressure to include person-centered planning, personalized housing, independent care management and other supports.

The level of consumer direction incorporated in HCBS waiver service delivery can be placed along the following continuum (higher numbers refer to greater consumer-direction):

Less Consumer Direction More Consumer Direction

Ability to Direct Care Received			
1	2	3	4
Ability to choose care providers	Ability to choose and change care providers	Ability to hire/fire care providers	Cash payments

The level of consumer direction offered differs across programs. The following reviews examples of different programs that correspond to the four levels of the continuum.

Level One: Ability to choose care providers. All waiver programs are required to provide consumers with a choice of service providers (Level 1), but not all states allow clients to change providers (Level 2) (Justice, 1993, 25). One way states encourage consumer choice is by requiring their signature on the plan of care or another form stating their choice.

Level Two: Ability to choose and change care providers. Ten out of 42 waiver programs studied by Justice (1993) reported that they allow consumers to change providers, although the wording varies from "Client may opt to change providers at any time" to "Client may request change in providers" (26-31).

Level Three: Ability to hire/fire care providers. The ability to hire and fire care providers offers a greater degree of consumer direction. The ability of consumers with impairments to assume responsibility for finding and managing care providers differs depending on their preferences and cognitive status. In a study of eight states that give beneficiaries the power to hire, train, supervise, and fire care workers, beneficiaries of all ages managed their services and derived significant quality of life and care benefits (Tilly and Wiener, 2000). However, this level of consumer control may have increased risk injury and fraud for individuals with cognitive impairments.

Level Four: Cash Payments. Cash and counseling programs provide cash allowances, coupled with information services. Theoretically, this should allow persons with disabilities to arrange and purchase the services they feel best meet their needs. To the best of our understanding, no states currently operate cash and counseling programs through their HCBW program. Four states (Arkansas, Florida, New Jersey, and New York) are or will offer cash and counseling programs through an 1115 Medicaid Demonstration waiver. In addition, some states offer cash payments using state-only funds. Austria and France have a tradition of using cash allowances to provide assistance to people with disabilities. The Netherlands and Germany added programs that offer cash allowances (Tilly and Wiener, 2000). In Germany, 85 percent of survey respondents who choose cash benefits reported that they did so to have greater control over their benefits (Runde et al. 1996).

V. QUALITY OF LIFE AND CARE IN HCBS WAIVER PROGRAMS

HCBS are often seen as desirable because they may lead to improved quality of care or quality of life. Quality of care and quality of life are distinct concepts that are often confused. While quality of life addresses the degree to which individuals are satisfied with their lives, quality of care refers to the degree to which the appropriate care that is given will improve or maintain the individual's level of functioning. It is important to clarify not only the difference, but also the fact that the two are not always compatible. Factors that may make it easier to assure the quality of care, such as strict regulations and larger facilities, can decrease the consumers' quality of life by allowing them less autonomy and freedom. Kane (1995a) states that while some experts believe that efforts to regulate the quality of long-term care have been successful, "few would be confident that we have so far created an environment that approximates a fair chance at an adequate quality of life" (Appendix B, p. 7).

Some state program administrators fear that the more home-like atmosphere possible in smaller residential settings will be destroyed by imposing regulations like those in nursing homes, and see the situation as "a trade-off between quality of life and quality of care" (Alecxih et al, 1996). However, deficits in the quality of care provided may negatively affect quality of life as well. Some studies have shown up to a 72 percent higher mortality rate for mentally retarded HCBS clients in residential care than that of institution residents. (Strauss and Kastner, 1996; Strauss and Shevelle, 1997). Although this conclusion has been challenged for validity (Lakin, 1998; O'Brien and Zafaria, 1998) and appropriateness (Decoufle, Hollowell and Flanders, 1998), it emphasizes the importance of monitoring health and safety of those consumers receiving services in the community.

Concerns around quality of care could be grouped into the following categories derived from a 1996 Lewin study of Colorado, Oregon, and Washington conducted for the AARP:

- *Difficulty of monitoring noninstitutional care*. It is more difficult to monitor the quality of care provided in the home or in smaller residential settings because they receive less public traffic and participants are dispersed compared to larger institutions. This problem has increased as the number of smaller residential settings has increased. For example, the number of licensed residential settings serving people with MR/DD grew from 14,700 when the 1915(c) waiver was first implemented in 1982 to 104,800 in 1998 (Prouty and Lakin, 1999). In Oregon, this criticism received attention within and beyond the state after a series of highly publicized incidents in adult foster homes. One county auditor reported that after unannounced visits to 40 adult foster homes, two-thirds were deficient on at least one of the quality indicators used, and in eight homes (20 percent) conditions required immediate reporting (Blackmer, 1994). This report recommended improved screening for new adult foster home operators, enhanced monitoring, more consistent imposition of sanctions, and greater coordination with citizens and professionals to identify problem homes.

- *Inexperience in monitoring noninstitutional care*. States have less experience monitoring quality in home and community-based settings. For example, many states have not established regulations or licensing requirements for certain types of residential alternatives. Nursing facility representatives argued that alternatives to nursing homes are not equipped to handle clients with higher levels of impairment. In their view, adult foster homes and assisted living facilities may become skilled nursing facilities that are subject to very little regulation. As a result, a facility with extremely limited staff can serve someone with a high level of service need. This, in turn, could threaten quality of care.

- *Impact of low provider reimbursement rates on quality of care*. States may see the reduction of rates paid to providers as an easy mechanism for controlling costs; and community-based care organizations may lack the organizational structure and lobbying power to fight rate reductions possessed by the nursing facility industry. One provider association representative in Oregon stated that the state is "balancing its budget on the backs of providers" (Alecxih et al., 1996). Many people argued that Oregon and Washington have a two-tiered home and community-based care system. Because of low reimbursement rates, the better quality home and community-based care providers tend only to accept private pay clients.

<u>Measuring Quality of Care</u>. Adequate measures of quality of LTC in general and HCBS in particular appear to be less developed than for acute care. A report from the GAO pointed out that the goals of LTC are not clearly defined, making it difficult to determine whether these goals are being met (GAO, 1994b). Furthermore, the different parties involved (program administrators, services providers and clients) define the goals of HCBS in different ways.

Outcome measures commonly used for acute care are not easily adapted to HCBS. Unlike acute care patients, the condition of LTC recipients rarely improves, and in many cases eventually declines even with high quality care (Kinney et al, 1994).

GAO listed a number of outcome indicators that could be used to assess quality of HCBS (**Exhibit 14**).

Exhibit 14

Outcome Indicators of Quality of Care

Functioning	Safety	Health	Client Satisfaction
Change in ADL/IADL status Ability to toilet as needed	Falls Burns Financial exploitation	Appearance of decubitius ulcers Infections Adverse Drug Reactions Symptom distress Weight gain or loss	Client perception of unmet needs Perceived quality of meals Freedom from fear Comfort Sense of control Freedom from unwanted disruption Preference for current living arrangement Duration of preferred living arrangement

Source: GAO 1994b, Table 3.

States' Efforts to Ensure Quality of Care. However difficult to measure, there are a number of ways by which states have attempted to ensure quality of care in the HCBS Waiver programs. They can be grouped into two basic categories: 1) licensing, certification and regulatory requirements; and 2) monitoring activities. The following elaborates on each.

Licensing, Certification, and Regulatory Requirements. Services provided by waiver programs are primarily unskilled, and do not have the same quality controls built in that many skilled services, such as nursing, do. Licensing can help to ensure quality by requiring that providers of certain services meet specified state standards for care or face license revocation. However, current licensing practices have limits since licensing is often limited to agencies providing skilled nursing services, leaving a regulatory "hole" with respect to unskilled LTC workers (GAO, 1994b, Kinney et al., 1994, 63).

A series of high profile abuses in Oregon may have induced some states to increase efforts to license HCBS providers. In response to concerns about abuses occurring in alternatives to nursing facility care, Oregon passed legislation in 1995 requiring anyone opening an adult foster home to receive training, pass a test, and undergo a criminal record check before receiving a license and starting operations.

Monitoring activities. The effectiveness of licensing and regulatory requirements at ensuring quality of care is impaired if states do not sufficiently monitor compliance. However, monitoring quality of HCBS services may present greater challenges than monitoring quality in institutional settings.

States typically rely on traditional monitoring practices, such as checking credentials and reviewing care records. The practice of on-site inspections offers another important means of monitoring the quality of home and community-based waiver services. The threat of unannounced inspections, as well as the example of other providers who have been penalized after such inspections, create incentives to improve the quality of care. However, states often do not rely on inspections because they tend to be expensive, due in part to the fact that care is conducted at many different sites (GAO, 1994b).

Case management can be another means of achieving quality care, particularly when case managers are assigned to monitor the quality of care received by their clients on a regular basis (Kane, 1995a, 1995b). This can hold true for a number of reasons. Regular contact with clients and their service providers allows case managers to ensure that services are being provided as intended (Justice, 1993). By regularly reviewing their clients' plans of care, case managers may become aware of deficits or inconsistencies in the care received (GAO, 1994b). In addition, case managers may be the first persons their clients turn to when they have a problem or complaint.

For several reasons, case management often does not achieve its potential as a means of assuring quality care. Large caseloads can limit the ability of case managers to detect poor quality of care (GAO, 1993). Prouty and Lakin (1991) report that among state programs providing Medicaid HCBS to the MR/DD population, the average number of cases per case manager ranged from 10 to 150 individuals, with a median of about 40. Another limitation lies in the lack of procedures to assess or address problems. In a survey of 75 case management agencies, Kane (1995a) found that while a third conducted regular client surveys and a third systematically tracked client complaints or problems, most did not have formal methods for assessing the quality of care provided or for correcting problems when they were discovered.

Providing mechanisms for handling *client complaints* is yet another way that states can monitor and assure program quality. Some states set up hot lines or ombudsman programs that consumers can contact with complaints about HCBS providers, which could trigger a state investigation. Client complaints, however, have real drawbacks as a means of improving quality of care. For example, the most vulnerable populations, such as those with cognitive impairments and those who lack adequate informal support, are unlikely to complain through formal channels. Consumers may also be reluctant to file a complaint against a service provider out of fear of losing services that are essential to them.

Some states are attempting to use *market forces*, rather than regulations and punitive actions, to improve the quality of HCBS programs. To cite one example, consumer-directed programs allow clients to hire and fire their own caregivers. In theory, this allows the clients the freedom to fire any caregiver that does not satisfy them. However, it is feared that many members of vulnerable populations may not be able to manage a care provider effectively. States may also choose to provide counseling to consumers about choosing providers or training on how to be an effective employer.

VI. COST CONTROL MECHANISMS IN HCBS PROGRAMS

HCFA and most states have been cautious about expanding their Waiver programs, especially A/D waivers, because of concerns of the extent to which pent-up demand will drive up costs. States have employed several means to try to control costs. HCFA has instituted several requirements that states must meet in order to have their Waiver program application accepted. For example, HCFA must approve maximum enrollment and expenditures before the waiver is approved. Also, HCFA requires that each waiver must be cost neutral. Since HCFA simplified the cost neutrality formula in 1994 when it removed the "cold bed" requirement, the number of waiver recipients appears to have grown dramatically, especially for MR/DD programs. MR/DD waivers programs currently serve approximately twice as many recipients as institutions. This would not have been possible if states still had to demonstrate that there was or could be an available institutional bed for every MR/DD waiver recipient.

All states must demonstrate that on average the cost of serving an individual under the waiver program is less than the average institutional costs on HCFA form 372, the annual statistical report required for each HCBS Waiver. Most states interviewed by Lewin as part of this study and the earlier AARP report indicated that they have little difficulty meeting this requirement. However, some of the more progressive states that are striving to serve their entire eligible MR/DD population through HCBS are trying to determine whether they are required to keep a nominal number of institutional slots open to serve as comparisons against the average costs under the waiver.

<u>State Cost Control Mechanisms</u>. States have employed a variety of mechanisms to try to control costs in their HCBS Waiver programs beyond the requirements established by HCFA. Most directly, some states have acted to limit program appropriations in state budgets, though most states include separate appropriations for the waiver in their budgets. Programs respond to these fiscal constraints by taking one of two courses of action: placing caps on spending per recipient or limiting the number of participants.[13] To accomplish the first, some states place limits on the dollar amount that can be spent per person, or on the average spending per person. They can also limit the hours of service provided per recipient. In addition, states control costs by placing maximum hourly or daily provider payment rates.

States also limit the number of program participants in different ways. Typically, states choose to limit program eligibility by degree of impairment or financial need. Many states also keep waiting lists because the demand for Waiver services is greater than the capacity of the Waiver programs. Some states provide services to individuals on the waiting list on a first-come, first-served basis, but many states prioritize the lists according to level of need for services. Targeting services to reach those most likely to be institutionalized can help to keep expenditures down (Greene et al., 1995; Greene et al., 1992; Greene et al., 1998).

<u>Additional Cost Control Options</u>. States employ a number of other mechanisms that can help control or limit costs. Examples of these mechanisms include the following:

[13] States have the ability to limit the number of recipients beyond the requirements made by HCFA. States can either not fill all the waiver slots that were approved by HCFA or reduce the number of slots requested in their next waiver application.

- Some states capitalize on funds from other sources to make waiver funds go further. Many MR/DD programs merge funds from multiple sources to create a "pool" of dollars that is available for a particular individual. Many aged/disabled waiver programs finance residential alternatives to nursing facilities by blending waiver dollars with funds from other sources, most notably Supplemental Security Income (SSI) dollars.

- Case management that is not limited to arranging services can also help control costs by limiting the services provided to those most at risk of institutionalization, and by monitoring clients to ensure that the services provided remain necessary. Case managers may also monitor providers to ensure that billed services were actually provided. However, we were not able to locate any studies that demonstrated whether these savings could be achieved.

- Prior authorization of services is another way of controlling costs. This mechanism requires prior approval for all services or services meeting a certain criteria (e.g., certain types of services, such as home modifications, or services over a certain dollar threshold).

- Some states, such as Oregon, control costs through nurse delegation. This mechanism allows nurses to train and monitor non-licensed caregivers to perform certain medical services, making the provision of these services less costly by maximizing the ability of non-professional care givers to provide care.

- Information systems that track client services by cost and use can be a useful tool in controlling costs. States with highly developed systems can monitor costs and intervene to adjust for inefficiencies in a timely manner.

- Some innovative programs have attempted to reduce costs by relocating groups of highly disabled clients to apartment communities or residential alternatives (Kane, 1995). This tactic may help overcome cost barriers related to trying to serve individual clients with substantial impairments in their own homes by creating economies of scale. However, this approach may conflict with recipients' desire to stay in their own home.

VII. EVALUATIONS OF HOME AND COMMUNITY-BASED CARE WAIVER PROGRAMS

Proponents of HCBS argue that care in the community is preferable to institutional care because it allows for higher quality of care and improved quality of life at a less expensive price. Unfortunately, Miller's 1992 conclusion, that the effectiveness of this program has not been rigorously evaluated, still holds true today.

Early studies of waiver programs found that while the average costs for waiver recipients were less than institutional costs, the programs did not appear to result in cost savings because, for the most part, waiver recipients would not have entered an institution because family members would have continued to care for them in the absence of the waiver (Clinkscale, 1986). This conclusion is based on studies of four individual waiver programs representing a range of populations and a comparison of states with and without waiver programs. The results of the evaluations of the individual waiver programs suggested that waivers might result in increased spending, while the national evaluation did not detect a significant difference in Medicaid long-term care spending growth rates.

An evaluation of waiver programs targeted to individuals in California and Georgia at risk of entering a nursing facility concluded that these programs were not budget neutral (Vertrees, Manton and Adler, 1989). This evaluation was based on data collected in the early 1980s.

A 1994 General Accounting Office (GAO) report examined HCBS programs in three states (Oregon, Wisconsin and Washington). This report made the following claim: "Home and community-based services have helped control growth in overall long-term care expenditures by providing an important alternative to nursing facility care, thus helping states exercise greater control over nursing facility capacity and use (GAO. 1994c, p.2)." GAO based this conclusion primarily on: (1) comparisons between the average monthly expenditure for someone in a nursing facility and someone being served in the community, both adjusting and not adjusting for other government expenditures, such as SSI; and (2) the fact that the number of licensed nursing facility beds in these states decreased slightly between 1982 and 1992, while this number increased by over 20 percent nationally during this period (GAO, 1994c). In this examination of the cost-effectiveness of home and community-based care, GAO did not consider factors such as total growth in Medicaid long-term care spending or differences in the populations being served by home and community-based care programs and nursing facilities.

An analysis performed by the Lewin Group (Alecxih et al, 1996) expanded upon the findings of the GAO report and conducted a macro-level analysis that addressed the effect of HCBS waiver spending on overall long-term care spending by the state. The three states studied (Oregon, Washington, and Colorado) reduced the use of Medicaid-funded nursing facilities well beyond growth rates that occurred in the rest of the country. In addition, these states served substantially more people in the community. Even in the most stringent analyses, in which adjustments were made for other government costs and national trends, home and community-based care resulted in substantial savings. Unfortunately, as the authors of this report noted, the findings in the report rely on a modeling effort that is strongly influenced by the assumptions chosen. Therefore, findings must be considered suggestive rather than conclusive.

Many states also conduct their own evaluations of Waiver program cost effectiveness. For instance, in 1994, Wisconsin compared waiver program costs with equivalent nursing home costs in a report to the State Legislature. According to its calculations, in 1993 the Community Integration Program (CIP II) and Community Options Program (COP-W) yielded savings of over $37 million for the state. Unfortunately, locating and summarizing all of these state-funded evaluations was beyond the scope of this project.

However, studies using Channeling Demonstration data (Greene et al., 1992; Greene et al., 1995; Greene et al., 1998) have found that targeting appropriate types of services to specific categories of consumers may result in reductions in institutionalization that justify the costs of the HCBS services. Greene and colleagues (1992) estimated the probability of transition from the community to a nursing facility, and found statistically significant reductions in nursing facility admissions for certain groups of individuals (i.e., those in wheelchairs who received nursing services, individuals with cognitive impairments who received home-health assistance, and individuals with functional impairments who received housekeeping or personal care services). In a later study, they simulated the reallocation of resources to maximize the potential to prevent institutionalization, and found that under the optimum service redistribution, the amount of time per person spent in nursing home care could be reduced by nearly two thirds (1995).

There is a much richer body of evaluative research about HCBS services in general than there is for HCBS waiver programs in particular. Leading studies have reached mixed conclusions on the cost effectiveness of home and community-based services. A number of studies, most notably those resulting from the National Long-Term Care Channeling Demonstration, contradict the assertion that community-based long-term care saves money (Weissert and Cready, 1989; Weissert, 1986; Weissert, 1988). A review of 32 studies of different types of HCBS programs reported that, on average, the overall cost of care provided by these programs increased by 13 percent without providing significant benefits to those served in the community (Weissert and Henrichs, 1994). Weissert (1991) reports that it is very difficult to save money with HCBS because "home care tends to serve patients who would not have gone into a nursing home whether or not they had received home care." (p. 69).

A recent paper summarizing the major findings on the cost-effectiveness of HCBS services as an alternative to nursing facility care, reached the following conclusions:

1. "The 'woodwork' effect seriously impedes the cost-effectiveness of home and community-based services.

2. Narrow targeting, low average benefit levels (taking into account availability of informal supports), and a strong emphasis on services provided in alternative residential facilities can increase the chances that home and community-based services programs will achieve budget neutrality.

3. The goal of achieving "budget neutrality" poses difficult trade-offs and often requires the imposition of unpopular limitations on access to home and community services.

4. Recent research is leading policymakers more and more in the direction of emphasizing home and community services in residential care alternatives to nursing homes such as adult foster care homes, assisted living facilities, and other board and care settings.

5. It is difficult-indeed it is virtually impossible-to design and conduct research that truly measures cost-effectiveness as distinct from "cost-shifting" from one program to another, from state to Federal funds, and from formal to informal care." (Doty, 2000, pp. 9-15)

VIII. IMPLICATIONS FOR AN EVALUATION

A number of implications for the evaluation of the 1915(c) HCBS Waiver program can be drawn from the literature available on the waiver program.

- The "exception" nature of the waiver makes for 240 distinct programs; therefore it will be difficult to get a representative sample.

- Lack of uniform data for programs is also a problem.

- It is unlikely that an evaluation will be able to account for all costs associated with providing care.

- The focus should be MR/DD and aged/disabled waivers, as they are the most prevalent.

- Different criteria should be used for the selection of MR/DD and aged/disabled waivers for evaluation because of the differences between the programs.

- Potential difficulties in measuring quality of care make it necessary to pay particular attention to this area.

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